4TH ANNUAL CONFERENCE OF THE RESEARCH ASSOCIATION OF MEDICAL AND BIOLOGICAL ORGANIZATIONS (RAMBO) ON THE SHARING OF HEALTH-RELATED DATA

Sevilleta Field Station

Socorro, New Mexico

April 19-20, 1999

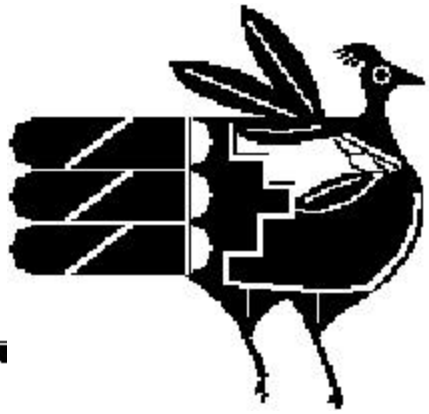


TABLE OF CONTENTS

Section 1 RAMBO's Beginnings and the Annual Conference

The Research Association of Medical and Biological Organizations (RAMBO) came about because of the need for—and the benefits of—using data from different disciplines to better understand specific health-related problems. First-year participants embraced a momentum to work together to examine the relationship between hantavirus and plague and global/regional climate patterns. They began meeting informally once a month to share and learn about available data resources. Every year in the spring, RAMBO "members" get together to review the activities of the past year, network with old and new attendees, and examine RAMBO as a changing organization.

RAMBO's fourth annual conference took place April 19-20, 1999, at the University of New Mexico (UNM) Department of Biology's Sevilleta Field Station near Socorro, New Mexico. Participants, many of whom have attended the previous three RAMBO conferences, represented UNM, state agencies, and other health organizations in Albuquerque, Santa Fe, and Los Alamos. (A list of participants is included in Section 9.)

At this year's meetings, participants heard about the changing approach to ecological research and progress reports on the US-Russian Hepatitis C study, the Statewide Immunization Information System (SIIS), and the Health Care Facility Database, a part of the Geographic Access Data System (GADS). Participants also reflected on the successes of RAMBO and discussed how the organization can continue to pursue its goals and not lose its unique energy.

The Sevilleta Field Station, site of the RAMBO get-away, is a long-term ecological research site serving visiting researchers and students studying the ecology, geology, and archaeology of the central Rio Grande valley. Current research projects are being conducted at Sevilleta in the areas of climate, mammal population and disease, and Geographic Information Systems (GIS) technology. These studies represent examples of the broad sets of data that, when correlated with other data sets, can provide an unusual, insightful view of health-related problems. This "outside-the-box" approach is one of RAMBO's goals.

Summary of Day 1

The conference opened with introductions. Many of the participants knew each other from the monthly RAMBO meetings or previous conferences. However, a number of first-timers attended.

Gary Simpson of the New Mexico Department of Health reminded participants of the importance of confidentiality of what is discussed during the conference. Participants were asked to sign a confidentiality agreement.

Jim Gosz of UNM's Department of Biology discussed the changing approach to ecological research in a talk entitled "Knowledge Networking in the Next Millennium." He was followed by Al Zelicoff

of Sandia National Laboratories, coordinator of the US-Russian Hepatitis C study. He presented a status report and some very preliminary findings, using a virtual reality-based diagnostic tool.

Summary of Day 2

On the second day, Gary Simpson reviewed the status of the Statewide Immunization Information System and its potential to reduce the number of outbreaks of infectious diseases by providing up-to-date, accurate immunization records. David Espey followed with an update on the Health Care Facility Database and Geographic Access Data System (GADS). He also presented some data already entered into the database. The facility and licensing information has never been available in one place before. Shirley Baros updated the group on EDAC's work to collect, organize, and mine medical data from the Indian Health Service (IHS) clinics.

Following this report, Gary created a list of all the collaborations, planned or existing, that have resulted from RAMBO members' sharing of ideas and resources. Discussion about RAMBO itself followed, as the group continues to try to define what makes RAMBO unique and why it has worked so well. Speakers for upcoming monthly meetings were also identified.

Section 2 Need for Confidentiality

Gary Simpson reminded the group that the requirement for confidentiality of patient information was one of the issues raised three years ago as a barrier to the success of this group or any one like it. Simpson presented a confidentiality commitment that participants signed to cover the two days of the conference.

This report has been reviewed and approved to meet the confidentiality requirement.

Section 3 Knowledge Networking in the Next Millennium

Jim Gosz, UNM Department of Biology

Jim started his presentation with quotes from several well-known ecologists, including Rosina Bierbaum and Rita Colwell (National Science Foundation [NSF]). These quotes illustrated the change in research approach that is being sought by federal funding agencies: the traditional approach to research, that involving a single investigator conducting a short-term, spatially limited study, must change to one that integrates research from many fields and is designed for longer-term study. The value of the national and international LTERs (areas set aside for Long-Term Ecological Research) has been recognized and has been a driver in this change. The new concept is one of an "environmental observatory" where many researchers of different fields are involved.

What's wrong with the traditional approach? The limitations of the single-investigator approach have been recognized; more value can be attained with interdisciplinary collaboration and integration of research.

The fundamental goal in ecological research is that understanding is necessary to manage our natural resources in a sustainable manner. But the challenges are complex: the environment is dynamic, spatially variable, biologically diverse; therefore, interdisciplinary research is essential.

Gosz gave a simple example of statistics showing the days of ice cover over Lake Mendota, Wisconsin, over 150 years. The number of data points make a difference—with long data sets, you can start to see patterns, trends, relationships to El Niño or La Niña.

Over 75% of the studies reported in US ecological journals are based on 1-2 years of study. Our current knowledge base is biased toward short-term results. These short-term results can be misleading.

Why do we do research this way? Gosz cited a number of reasons, including historical ones: scientific careers are based on publishing studies—the more the better (shorter studies=more publications). As funding agencies' agendas change, research project proposals follow the money. Short studies mean fast results, and sometimes fast results are a stated goal. Many short studies can also mean greater funding over a scientific career.

Problems with the Traditional Approach

In typical research scientists focus on small spatial scales—e.g., 1 m square—or 1-2 species only. It has a single-discipline emphasis. Such study does not reflect the complexity of a biosystem.

Another issue is poor data management. Journals do not have the space to publish raw data, so the data is not available. Older raw data is sitting on hard copy in file drawers.

Still another issue is scaling. Data from a meter is too small for managers to use to manage ecological resources well. The capability is needed to go from meter-square data to kilometer-scale data, or even to the Rio Grande valley scale, or the state of New Mexico, or a region of the country or world. We need to be able to incorporate data into models.

We must have data that is multiscale, interdisciplinary, and long term to build models and make good decisions about resource management.

Changing conditions on the Sevilleta—there are many variables here that can be simulated and used to build data.

The LTER sites like Sevilleta offer the environment and opportunity for study of multiple species and their interactions, integration of many temporal scales and spatial scales, multidisciplinary projects, and availability of large archives of data. LTER sites become research platforms or "ecological observatories." As in oceanography, where many researchers of varied disciplines have to collocate on a ship, and thereby results a research platform, so Sevilleta is also a research platform. The data from many disciplines of researchers who come here can be integrated. Strategies must be developed that will bring people together.

Information management is critical. Data that has no QA/QC and no organization is throwaway data. The value of information content decreases with time. Gosz quoted an African saying, "When an old man dies, a library burns."

The current situation is only going to get worse. The complexity of data requirements needed is increasing. There is a wide array of information that needs to be integrated.

Unanticipated values arise from the data, as the hantavirus outbreak demonstrated. Available data sets can be used when unexpected problems come up. We can analyze old specimens for new things.

The US LTER Network Mission

The LTER program was first set up in the 1970s to create a legacy of well-designed and documented long-term experiments for use by future generations. The change in scientists and their approach to research is now evident. Gosz gave an example of a project set up to be a 200-year study of large woody tissue decomposition in a forest. A typical approach would be to study a small area for 1-2 years, observe the decomposition of some objects, and project the composition of other objects based on those observed. The culture change here is the foresight to set up a study that future generations can continue.

Space for time substitution is the way it has been done—you do not have time, so you look at the space and guess how or compare one thing with another to see how it came to be.

Because the value of the long-term data is being recognized, NSF is now beginning to fund LTER-type projects.

LTERs are core research areas—fundamental ecosystem processes can be studied there. These studies require a team effort. Now proposals must have multiple disciplines involved; these studies form the basis for cross-site experiments. One can study such subjects as the factors that control populations or species types, invasive species patterns, control of organic matter accumulation on the surface, control and patterns of disturbances (fires and droughts, etc.).

For the first time, two new LTERs are urban sites—Baltimore and Phoenix. These sites will use the same core areas for study. The importance of cross-site synthesis is being recognized—decomposition, spatial and temporal variability, climate variability, stream characteristics. These and other data can be compared long term across sites.

The NSF has a new program to study Microbial Observatories. What is the relationship between microbial diversity and plants vs. physical diversity vs. chemical diversity? Multiple data sets are required to answer these questions.

Another project is the National Ecological Observatory Network: a network of sites for studying biocomplexity at all levels, involving cutting-edge research, innovative cross-site and short-term projects, and partnerships with existing networks.

The next competition coming from NSF will seek proposals to build/integrate data from LTERs, museum collections, individual scientists, field stations, etc. The vision of the NSF for a bio-observatory is a collection of places that are networked. Gosz expects them to ask for a theme, like a region (Great Lakes) or type (desertification)—such a project could network Jornada, Sevilleta, the New Mexico Museum of Natural History, Los Alamos National Laboratory (LANL), the Forest Service, national parks, the Departments of Defense and Energy, who are large landholders—many partners. Multidisciplinary studies could include species discovery, disease risk assessment, global climate change, agricultural pests—these are results that can come from new networks.

This is not only a national initiative; it is taking place in Europe too. In the UK there is a project called the No LIMITS project; they see a fragmented approach too. International LTERs (ILTERs) also exist.

The collection of long-term data has made LTERs become “national treasures.”

These new interdisciplinary, cross-site studies can help remove political barriers and historical tensions.

Discussion

Attendees brought up a number of questions and different topics for discussion.

Q. The scientist has to be different to work successfully in this approach. Has that happened?

A. Those people who do not change will continue to generate valuable science. But the new kind of scientists are coming through the system. The International Biological Program (IBP) of the 1970s was really the root of the change. The change is coming from association with people of IBP era. Those graduate students are now scientists training other graduate students (LTER program came out of IBP). Most transition at the PI status level is controlled by the system, not by revolution, so you train the kind of leaders you want to take over science research/leadership.

Q. The science that comes from research at LTERs is not related to human health yet—how can we use the body of data we have in the health arena?

A. The 2 new urban sites are the breakthrough into sociological/economic science. Now we need to get people working in those areas to work in the new LTERs.

And NSF and NIH (National Institutes of Health) may come out as soon as the end of summer with an RFP on the ecology of infectious disease. So this is a way to make the interdisciplinary studies happen. This may be a good opportunity to explore sanitation and hepatitis A and zoonotic diseases, etc.

Q. In scaling up in space and time—how rigorously have people looked at taking data from 1 m, identifying a larger space, describing goals, and saying 'what data do we need to get to accurately scale up? What are the rules?'

A. The remote sensing people are leading this direction. There is a lot of research going on in how to aggregate data without losing information. To scale up, how many parameters do you need in 1 sq. meter research? First you gather data, then build a model, then spot-check somehow to determine the accuracy of model and scale. These are nonlinear relationships, therefore very complex. It's difficult to get accurate results.

Q. How do we best apply what we've heard to the health arena?

A. Looking at data over time in a different way to see what we can find.

Q. Getting people who can look at things in that way is difficult. The health system does not have a structure to encourage and make happen the looking across disciplines.

A. It took time in this community—it was novel challenge. People who liked it stuck with it and became leaders. Only in the last 10 years have we started to embrace networks. It's a chicken and egg phenomenon: you had to have the interest, get funding, and show value....

Comment. Advances in technology like GIS were drivers. Technology is enabling the success of networks.

Comment. The traditional way of research and its problems are inherent—lack of funding, publish or perish.

A. This is a human problem, not a science one. Individuals gathering long-term data is still only a first step. Some data is collected, but there is nothing to relate it to, on the scale useful for building patterns.

Comment. Need a sum of the parts that will be more than a sum of the parts. GIS provides that somewhat, for other disciplines.

A. GIS is a tool, but you have to use it with something else.

Comment. Atmosphere and mortality from respiratory disease—that could be studied in the 2 new urban LTERs. And relationship to asthma. Also hypothermia and mortality experienced in geriatric populations.

Comment. Monitoring is not set up in many cases. Modeling does not work in some situations, but monitoring does.

Comment. Integrating both can be beneficial.

A. Sometimes you have people who develop monitors who just want to monitor and go no further, but the limitation is that they have no predictive capabilities.

Comment. The Health Information Alliance is linking repositories of data, not looking at predictive modeling or acquisition of new data; just linking.

Comment. In the public health arena, large data sets from the Centers for Disease Control (CDC), SEER, other surveys, are publicly available and distribution is promoted for the public to mine. Availability has increased the value of these data sets. To the extent that we can achieve data sharing at the State level (one of the driving forces behind formation of RAMBO), we also will see the increase in value of the data.

Comment. That's how RAMBO got started—to look at how you cross the multidisciplinary boundaries. NSF is even talking about adding money to funded projects for training people to work with people of other disciplines and learn their language. New Mexico is ahead in this area.

Comment. But we can't do it as well if it's not a goal of the agency, or if there is not enough funding. Many data sets are available out there already. LTER has the social organization and funding that facilitate communication.

Section 4 Report on US-Russian Hepatitis C Study

Al Zelicoff, Sandia National Laboratories

This US-Russian Hepatitis C study is being sponsored by the US Department of Energy under the Office of the Assistant Secretary for National Security and Non-Proliferation. It is an epidemiological study conducted as a model for strengthening the Biological and Toxin Weapons Convention (BTWC). This treaty prohibits the stockpiling of biological materials for hostile purposes; a treaty country cannot have types and quantities of biological materials that have no justification for peaceful uses.

Most biological agents have dual uses; they are harmful as well as therapeutic. The US Department of Agriculture has 54 approvals for the botulism toxin (botox). It is used as an anti-wrinkle agent and has been administered to children with cerebral palsy to reduce muscle spasms. The therapeutic use has increased to the point that there is now a botox B for use on people with antibodies for botox A.

The two-page BTWC treaty entered into force in 1975, but had no monitoring regime. Article X of the treaty states that all parties will exchange equipment, materials, and information, and there have been review conferences every 5 years.

By 1991 there was clear evidence of stockpiling. In 1979 in Yekaterinberg, Russia, a number of people and sheep died from pulmonary anthrax. There was an international meeting of physicians there at the time and so the information leaked out. The US State Department became convinced that this was a BTWC treaty violation, because there is a biological plant in Yekaterinberg. Russia said the people died from eating bad meat. But it is very hard to get pulmonary anthrax that way. In 1991, Russian President Boris Yeltsin admitted to a leak from the biological plant and violation of the treaty.

That incident motivated the creation of a committee to work on a monitoring regime. Since 1995 the team has been trying to structure a protocol for verification. For chemical weapons, the verification regime is 300 pages, and 400 inspections have been conducted under it. But chemical weapons are manmade, not naturally occurring, so 1 molecule of a forbidden substance is too much. Their task, though difficult, is still much easier than one focused on biologicals.

A lot of false positives occur in biological inspections. In his own laboratory, Al swiped the threshold and other innocuous places and found anthrax. The probability of false positives is much higher than in the chemical regime.

The US has conducted a series of mock inspections. One reason for the inspections is to help determine if there is any other viable monitoring method other than inspections. The mock inspection turned up many sites that would be in violation of the treaty. Why? It's hard to keep up with small samples, and the ubiquity of working with biological materials. Universities (some of whom flunked) may prefer to cease working with sensitive materials if there is a strict inspection regime.

The BTWC and Infectious Diseases

What onsite activities make sense for the BTWC monitoring regime?

Outbreaks of suspicious diseases is one. An example of a suspicious outbreak was hantavirus. It was in New Mexico, which is heavily funded by DOE—could it be a test of a new biological weapon? an accident, intentional use, or test?

Monitoring of global emerging diseases: the notion of expanding monitoring capabilities and the ability to rapidly share data might be appropriate for the BTWC monitoring regime. So the committee picked as an experiment: hepatitis C.

There were political objectives and technical ones:

- eventually work with Russian biological warfare sites; build cooperation with Russian nonnuclear sites. 10K people/site work at Russian "public health" sites.
- demonstrate the utility of disease monitoring
- develop the US-Russian telecommunications system to 256kb bandwidth and full audio/video capability over the Internet

The Hepatitis C Study

The study, formally titled the "Cooperative Epidemiology and Disease Monitoring (CEDM) Project," involves random selection of emergency room patients in 3 New Mexico communities and Chelyabinsk-70 (Snerzinsk). These patients are asked to fill out a 176-question survey. They are also tested for hepatitis C. The target is 2000 patients in each country, and data gathering started in November 1998.

Partners in the study are the New Mexico Department of Health, UNM School of Medicine, Sandia National Laboratories, LANL, World Health Organization, Russian Federation Nuclear Institute of Technical Physics at Chelyabinsk-70, Chelyabinsk-70 hospital, and 3 New Mexico hospitals (Los Alamos, Alamogordo, and Silver City).

This project has worked: doctors of different specialties working in emergency rooms in two different countries speaking two different languages can do it.

The project has attracted other interest. A Russian institute in Yekaterinberg wants to get information and is interested in doing a joint project. Kazakstan wants help to do a hepatitis C study, but also has expressed interest in setting up an epidemiological study and a long-term monitoring station at the suspected site where Russia dumped anthrax and smallpox. This could be done, with possibly only a few hundred thousand dollars. Al said he has also submitted another pre-proposal to use the same survey and do cross-country comparisons of hepatitis C for Thailand and the UK.

Al presented some very preliminary data from the 700 cases obtained so far in New Mexico. Data indicate that so far, hepatitis C is more widely prevalent than thought, especially in southern New Mexico.

Al demonstrated the graphical analysis tool the team is using to look at the data in another way. The tool used is derived from Muse, a virtual reality application that lets you view and rotate objects in 3-D. Because you can see the data spread out in patterns or focus on one individual, this tool lets people who are not medical experts theorize and test their hypotheses and then make new correlations.

The Russians will be doing traditional statistical analysis and the US will use this tool.

This project has led to others: a potential contract with VECTOR, the world's largest biological facility, for a hepatitis B and C study. And the UFIT project: a contract with VECTOR is hopeful for a study on Undifferentiated Febrile Illness with Thrombocytopenia. Al will be attending a meeting in May with VECTOR representatives and others.

In the joint study:

- we've done great research
- generated good data
- demonstrated that the activity meets the Article X issue of sharing.

Discussion

At the last RAMBO meeting, when ideas to study undifferentiated febrile illness were discussed, one snag was the Navajo objection to sending any samples off the Navajo reservation. (Most of the 100 cases were from the Four Corners [Navajo Reservation] area.) Non-Navajo samples can be shared—but the group must think about how to deal with this and similar issues. The Navajo are suspicious of sending the samples off. It's also a spiritual issue for them. Those involved in the study knew they had to include the people in these discussions. The original contact in the Navajo Nation's Division of Health was very supportive. But he has moved to a new position. There are economic issues too—the Navajos were hurt by the hantavirus scare.

Gary said it took only 19 days to determine what hantavirus was. The last previous outbreak that could have been suspected of being a bioterrorism attack—Legionnaire's disease—took 7 months to identify.

If the UFIT study does not happen, at least the cooperative relationship with several Russian institutes is established.

Gary wants to have a statewide hepatitis C consensus conference to look at intervention strategies. One intervention strategy is to have hepatitis C patients avoid hepatotoxic drugs and alcohol. But it has not been clearly demonstrated that alcohol accelerates liver damage. Previously unsuccessful attempts at intervention could also be examined.

Gary summarized what it known about hepatitis C: it is blood-borne (needles, blood transfusions, violent sex, surgery). It has been in existence a long time and occurs worldwide. Hepatitis C is

estimated to affect 1.8% of the national population. It is more prevalent below the poverty level. But there is no specific New Mexico data.

In analyzing this New Mexico study, consider also that people entering emergency rooms are considerably sicker and may be getting their primary medical care from the ER rather than a physician.

There are also implications in looking at the cost of treating hepatitis C patients. How many will require liver transplants? Some gastroenterologists say hepatitis C patients should also be vaccinated against hepatitis A and B. This will cost a significant amount. So, should these patients be identified? If you have hepatitis C, and you get hepatitis B, will you be more likely to require a transplant?

Liver transplants, cancer, and end-stage liver disease—the number of cases will triple in the next 8–10 years. There is some data that hepatitis C patients who get acute hepatitis A will fair very badly. Hepatitis C patients are also more susceptible to hepatitis A and hepatitis B.

The proposed consensus conference would address such questions as who will be treated? Who will pay for it? Treatment using the drugs Riboviron and Interferon A will be very expensive. The future of a hepatitis C vaccine is not good, as hepatitis C is highly variable, has multiple genotypes, and a high mutation rate, on the order of HIV. Health care providers must develop a patient care model. There are tens of thousands of cases suspected in New Mexico—a very different disease from HIV.

An Internet Visit with the Russians

During the evening of April 19, Al conducted an Internet telephone call to Russian colleagues at the Russian Federation Nuclear Institute of Technical Physics in Chelyabinsk-70 (Snerzinsk). Al's laptop computer screen showed RAMBO attendees in one window and Sergei Petunin, Konstantine Kuznetsov, and Nikolai Baturin in another. Attendees viewed in real time as greetings were exchanged; Gary asked several questions about the results gathered so far at the Russian site of the hepatitis study. The answers were similar to those obtained from the New Mexico data thus far. The Russian institute is facilitating work with the local hospital on the study.

Section 5 Status of the Statewide Immunization Information System (SIIS)

Gary Simpson, Department of Health (Viewgraphs are included in Appendix A.)

Immunization of children can greatly impact the health of a community. The need for a Statewide Immunization Information System is compelling—this need brought Gary to the first RAMBO meeting. Immunization can save $14 of hospital costs for every $1 spent on immunization.

The SIIS is fundamentally an information management problem. Typically a child has 6–8 doctor visits in the first 2 years of life, so the opportunities to provide immunization services already exist. But parents never have the records with them; if they do, the records may not be up to date; so doctors do not know, and sometimes give the same vaccination again. In addition, we know children on average access immunization services at 3–4 different sites. So how do we capture the data accurately, reliably?

The genesis for this project started here at Sevilleta after a talk Gary had with Sandra Zink of LANL about tuberculosis and the TeleMed project. The Northern New Mexico TeleMed Project allows each site to keep its own records but the sites are networked, so a virtual patient record is created. This concept gave birth to the Statewide Immunization Information System Initiative. Its objective: immunization, age-appropriately, of 90% of New Mexico children and high-risk adults by 20??.

The major question: how do we integrate existing records of immunization?

If we can immunize 90% of the children, we will not have outbreaks of vaccine-preventable infectious diseases. Now, we immunize about 70% of the children we know of by age 2. Mortality from infectious diseases in the US was approximately 800 per 100,000 in 1900; it has dropped tremendously during this century.

About 12 different systems need to be integrated to get the needed data; 18 partner organizations are involved. One of the questions asked is "What do the providers want the system to do?"

Some requirements that have been defined are:

- Enrollment at birth. 96-98% of births are reported now. Needs to start at birth.
- Hepatitis B vaccination needs to take place at birth.
- Focus on vaccine-preventable infectious diseases for children.
- Cradle-to-grave records.
- Timely collection.
- Flexibility and ease of use.
- Accuracy of data.

There are currently 14 vaccine-preventable infectious diseases, but new vaccines and vaccination schedule changes are predicted to occur every 6 months. The provider must know what to give, what the current recommendations are, the combination of vaccines that are available. This system should be able to handle and make available all these records:

- vaccine inventory and any recall information
- GIS information/applications
- provider-user graphical interface

- confidentiality

Technology trends are making it easier to integrate distributed databases. CORBA (Common Object Request Broker Architecture) is an interface that enables easy use of distributed databases.

With the Internet-based Patient Identification Service, a part of SIIS, you can search for a patient on 20 different identifiers. The Northern New Mexico TeleMed Project, funded by the Department of Commerce, has been a test case; it will link 16 rural clinics with 2 regional hospitals. The major problem has been getting GTE and US West to connect, and this has recently been done.

The climate is changing—this effort can lead to national registration efforts. CDC took a pounding for promoting national registration and immunization budgets were cut, because national registration is perceived as a "big brother is watching you" project.

Discussion

The issue of unscrupulous use of records came up. There is a very serious problem with vital records, a constant fight between the need for security and for convenience. Betty Hileman gave examples of identity theft problems. Forty problems were reported in New Mexico in 1990, and now there are 4–5000 a year. Identities are being assumed, credit being wrecked. Birth certificates are stolen and sold to foreigners. To fight this growing problem, the New Mexico Department of Vital Records has created a fraud position.

Betty pointed out that New Mexico public health policy does not discriminate against people from other countries—we want them to be treated and vaccinated. But the information that is needed for health purposes is also wanted by the Immigration and Naturalization Service (INS) because the information the patient gave to health officials may have been stolen.

Gary stated that the most robust of systems will have 20 fields—this will help with identity problems. You can design the system so the false positive rate is low; though the false negative rate may be high.

Section 6 Update on Health Care Facility Database and Geographic Access Data Systems (GADS)

David Espey, Department of Health (Viewgraphs are included in Appendix B.)

Two years ago a work group convened to address the issue of gathering and maintaining information on health care facilities. The idea was to draw on existing data systems and create a publicly available resource that could be accessed over the Internet. There must also be an update plan that includes when the database is updated and by whom. The Health Policy Commission (HPC) had a mandate to develop a similar system that would also include individual health care providers.

This idea/task is fairly simple to do: to provide highly valuable information that is not available elsewhere. There was no single source of data existing, but pieces of data were available in many agencies—Department of Health, New Mexico Tumor Registry, HPC Division of Government Research, Earth Data Analysis Center (EDAC), IHS, Medicare, others. So a work group formed with representatives of 7 agencies. The work group has held 6 meetings in the last 2 years. They have a consensus to develop a facility database of all inpatient facilities, public health offices, primary care centers, IHS facilities, and other federal facilities (Veterans' Administration and Air Force hospitals).

The work group has developed a draft database, which David presented to the attendees. The primary purpose is to have information available to persons involved in health services research that has a GIS component.

The draft database currently contains:

- facility ID information
- licensing information
- bed capacity
- services provided
- personnel numbers by medical discipline

A number of issues are still to be resolved, such as how the database can be updated in a reasonable way. Licensing certification is one source of updates.

Other issues include:

- Distribution—Internet is the ideal way of sharing the information.
- Restrictions—HPC's current plans are to have GADS restricted to researchers, even though it should have no controversial elements.
- Maintainability—should XML be used as the platform for ease of maintainability?

Shirley Baros said EDAC has a contract with HPC to maintain the database for 5 years. EDAC will be working on distribution; now there are 4 different databases to maintain, so that specific user groups can see only certain information (for security purposes). Shirley would like to warehouse the data, extract the redundancies, and make available what researchers need. She thinks this task is doable in the short term. EDAC will look at creating a Web site fairly quickly so people can download and save what they need. Shirley thinks they can achieve these goals quickly.

The data will also be archived each year so the records of license changes will be preserved.

Discussion

David said that another goal of GADS is to create an individual provider database, but maintaining it would be very difficult. There are databases that already exist, such as the Board of Medical Examiners list. But physicians can be licensed in many states. Or not even licensed here at all. Gary pointed out that the New Mexico Medical Society's database is more accurate and up to date. But this database is primarily for private providers, not government providers.

Several attendees had suggestions to address the updating problem. Someone suggested that the interface incorporate a way for people to send in changes. The problem of copying databases magnifies the update problem: if I have a copy of your database and you correct yours, how do I know that mine is out of date now?

Catherine Macken said LANL's influenza database is updated monthly. With electronic databases it is fairly easy. She stressed the importance of keeping a log of changes of every field, what the changes were, and when the change was made. This log has proved really critical.

If maintenance is critical and gargantuan to design, how do others do it? Here is an opportunity to learn from others—think outside the box—as well as WalMart does inventory.

Terry Yates said he (or people he knew) really did talk with WalMart managers about how they manage inventory —but WalMart people are cautious about sharing information because of competition.

Fred Pintz mentioned that Dave Forslund showed him the Clinical Observation Access Service. This system has a capability that should be explored.

Gary applauded David's project as an example of a collaborative system that RAMBO members can work together on that can come together fairly quickly, and be a success and building block for RAMBO.

Section 7 Update on EDAC Project with IHS

Shirley Baros, EDAC

EDAC is at the end of the first year of a 5-year contract to work on NICOA (National Indian Council on Aging). They work with IHS on diabetes and characteristics of diabetes in the Indian population, specifically the elderly. IHS has extensive patient records. Problems have included privacy, confidentiality, how to get data; it has taken 8–10 years to get data from IHS. Cimmaron Medical Informatics, the other subcontractor (developer of the RPMS database that IHS uses for health records), has built an extract program to access RPMS and extract 245 fields of information that are useful. Not all of the clinics have provided the same amount of information because they were opened at different times.

The project uses 5 clinics for a test; the test will involve data mining on elements that clinicians are interested in. Information will be provided back to the clinics. Another project goal is to get GIS-useful data. The early goal is simple analyses of data, like charts.

The project would like to add 50 clinics per year for the next 5 years, for a total of 250 clinics, and provide them with useful data central to diabetes issues.

Shirley said the test of 5 clinics is doable. She envisions setting up a SQL server and data warehouse and will probably use MS Access and Excel, using Visual Basic as a query builder. Access will be over the Web with password protection, at least for the first year. Reports will be valuable to IHS to get funding, for reporting to Congress, etc.

She said those involved in the project have learned a lot about people, politics, and trust-building. There were key people at key places who were willing to look outside the box, and willing to add GIS as a component—a new concept.

Section 8 RAMBO Organization Issues

RAMBO-Related Projects and Organizations Involved

To start out the discussion about RAMBO as an "organic organization," Gary listed the efforts under way as a result of RAMBO—collaborations facilitated or initiated by this group over the last year.

- SIIS
  - NNMRTP
  - Medical Society/EMR
- Cirrhosis/Hepatitis C
  - Hepatitis C Working Group—will host hepatitis C consensus conference on primary care treatment and who is going to pay for it
  - New Mexico Office of Medical Investigator—archiving cirrhosis specimens
  - Cooperative US-Russian Study on Hepatitis C
  - New Mexico Tumor Registry Study
  - Proposed Thailand Study—extension of US-Russian Hepatitis C study
- Alliance for Improved Senior Health (AFISH)—goal to immunize over 70% of at-risk seniors in specific areas for flu and pneumonia
- TeleMed/Tuberculosis
  - TIMS Interface for importing mycobacteriological lab data will share with every other public health service in the country.
  - Border TB Proposal—use/sharing of tuberculosis medical records by neighboring states (New Mexicans are getting care in bordering states, so the New Mexico records are not always accurate).
- EDEN/Hantavirus Uplink—when we had 2 early hantavirus cases last year, we did the videoconference link to 40 communities with 12 days notice. (EDEN is the Electronic Distance Education Network of UNM.)
- GIS/DWI/Crash Analysis/Drive-up Closure—plot geographical code locations of past car crash locations and compare with recent/future crash locations to see if the distribution of crashes changes after drive-up liquor windows were closed.
- Consortium for the Study of Emerging Threats
- Hantavirus studies
- UFIT (undifferentiated febrile illness with thrombocytopenia)—molecular diagnostics/LANL/VECTOR. VECTOR has agreed to analyze archived samples.
- HealthAlert Initiative—real money to develop a telecommunications infrastructure for communication over distances (like EDEN)

- Ethical Issues Working Group—entirely grew out of RAMBO
- Health Care Facility/GIS Project (GADS)
- Epidemiology for early outbreaks—population-based surveillance

Organizations that have been involved in these projects:

- New Mexico Department of Health—Vital Records, Public Health, Scientific Laboratory Divisions
- University of New Mexico—Dept. of Biology, School of Medicine, EDEN
- Los Alamos National Laboratory (LANL)
- Sandia National Laboratories
- New Mexico Medical Review Association (NMMRA)
- Earth Data Analysis Center (EDAC)
- Indian Health Service (IHS)
- Presbyterian Health Services
- Lovelace Health Systems
- St. Joseph Healthcare
- New Mexico Medical Society (NMMS)
- Health Policy Commission (HPC)
- Behavioral Health Research Center of the Southwest (BHRCS)

Gary cited the example of the beginning of HealthAlert. Everyone came, no one said 'no'; this demonstrates a real change in attitude toward interagency relationships. No one asked about how much money was needed or complained about taking resources away; it was an automatic response to say "so-and-so should also be involved." Barriers have been broken down—it seems easier to do the work. Relationships have begun to allow access to resources.

Discussion began with the question: Can we find a way to further break barriers without breaking the law?

Betty Hileman said that in the past three years she has been able to provide almost everything that was needed by RAMBO collaborators with little cost in resources. But the basis of this working together is the individual relationships she has with RAMBO people. The next step is to develop the process of interagency sharing, outside of the people relationship, without breaking laws or regulations.

Gary pointed out that there is no institutional way to engender trust, so perhaps relationships **are** the answer. But RAMBO may be a way to link institutes—through relationships. The number of people, types of people that are involved—that is a model of an organic organization that is

maturing. This may be what RAMBO teaches—that relationships make it work and there may not be much more beyond this. But other groups can do the same thing locally.

Betty said she has become more willing to think about how can she share what is needed by others and still protect what needs protection.

This year's attendees still feel that it is appropriate to take stock, at least yearly, of what the value of this group is and why it has evolved the way it has.

Future Plans and Direction

The group listed three items for discussion: timing of this meeting, the Web site, and future programs.

Scheduling this Retreat

It was agreed that a lot of RAMBO regular attendees were not able to come to this meeting. Sometimes there is no best time, because everyone is busy, but the group decided to pick dates earlier next year—some time around Thanksgiving if possible, but certainly not later than the first of the year.

One attendee suggested a quick e-mail questionnaire to determine what people thought about this year's date and agenda and to solicit suggestions.

Several people thought there should be more time for brainstorming and talking about future collaborations, networking, and interfacing more. The real power of the group is collaborations—where can we combine databases to get data that is not available yet? In the previous two meetings, the attendees did some planning. This is the first annual meeting at which there has not been a problem to address: this meeting agenda was a group of update reports. One suggestion was to gather data and bring it here, and do the analysis and mining live here.

Like the border tuberculosis issue: is there really a conflict with INS? Maybe they are just as interested and looking at the problem in a different way. It would be interesting to see, to pose the questions of what they do and how they look at things.

A balance of what's going on and planning for the next year was also suggested, so people can let the information incubate.

There are other RAMBO-like health-related organizations that are not progressing the way RAMBO is. These organizations are more focused than RAMBO, but are still interdisciplinary. Is RAMBO at a point that it understands enough to interact with other large interdisciplinary groups? What can be exported and imported from other groups?

But the group has explored the RAMBO phenomenon over time and still does not even have a vocabulary to describe what has happened. But members still feel committed to try to understand and describe it.

One member pointed to other groups that work that were formed for one specific purpose. They are the MAD-type groups (Mothers Against Drunk Driving)—single-focus. RAMBO has the intense energy of the single-focus groups. RAMBO has more of the energy even though it does not have a single focus.

It was agreed that at the end of every meeting, the question will be posed: "what are the implications for interdisciplinary research and action?" and the attendees will discuss possible collaborative efforts.

Suggestions for others to get involved in RAMBO included the INS, FBI, community planners (especially those familiar with border issues), as well as a policy specialist.

Suggestions for Web Site

Gary will send out e-mail asking for suggestions to improve the Web site. Some suggestions were

- adding hot links to our organizations to show partners
- adding a list of collaborations
- adding a way to send comments
- registering the site in search engines

It was agreed that the Web site should be reviewed at a monthly meeting.

Monthly Meetings

Tentative speakers for upcoming meetings were assigned:

May—Sandra Z. is getting a LANL person to speak.

June—Carolyn Thompson—developing a new vocabulary to describe initiatives like RAMBO.

July—Web site review.

August—Al R. will get a speaker.

September—Terry will get someone on evolution of humans in the Western Hemisphere.

Oct.—focus on finding new links between ecological work and health issues; what kind of databases are available to look at, and look at GIS.

October or November—Rick Osfelt—Lyme disease—Bob will try to get him in the fall.

Dec. or sometime in fall—Shirley Baros would like to get someone who can give perspective on interesting emerging technologies related to remote sensing techniques, GIS, and new satellites, and how they can relate to aspects of native people and health and lands. Also includes global databases that are available or are coming.

RAMBO has given attendees the ability and willingness to look for the ways something can work, and focus on success—within the group and especially outside of the group.

Section 9 List of Participants

Shirley V. Baros
EDAC
UNM
Bandelier Hall West, Rm. 111
Albuquerque, NM 87131
Ph: 277-3622 ext. 237
Fax: 277-3614
sbaros@spock.unm.edu

David Espey
NM Dept. of Health
625 Silver SW, Suite 200
Albuquerque, NM 87102
Ph: 841-5862
Fax: 841-5865
davide@doh.state.nm.us

Jim Gosz
Dept. of Biology
UNM
Albuquerque, NM 87131
Ph: 277-2265
jgosz@sevilleta.unm.edu

Rose Hessmiller
1605 Silver SE
Albuquerque, NM 87106
Ph: 842-6495
roseh@unm.edu

Betty Hileman
NM Dept. of Health
P.O. Box 26110
Santa Fe, NM 87502
Ph: 827-2342
Fax: 827-1751
bhileman@health.state.nm.us

Mary Houdek
NM Dept. of Health
P.O. Box 26110
Santa Fe, NM 87502
Ph: 827-2343
Fax: 827-1751
mhoudek@health.state.nm.us

Sandra Lapham
Behavioral Health Research Center
of the Southwest
4600-A Montgomery Blvd. NE,
Suite 101
Albuquerque, NM 87109
Ph: 830-3099
Fax: 830-3408
slapham@bhrcs.org

Catherine Macken
LANL, MS K710
P.O. Box 1663
Los Alamos, NM 87545
Ph: 665-6464
Fax: 665-3493
cam@t10.lanl.gov

Sheila Molony
LANL, MS M704
P.O. Box 1663
Los Alamos, NM 87545
Ph: 665-1585
Fax: 665-3891
sheila.molony@lanl.gov

Alice Nelson
Albuquerque High School
Ph: 268-0208
nelson@swcp

Robert Parmenter
Dept. of Biology
UNM
Albuquerque, NM 87131
Ph: 277-7619
Fax: 277-5355
parmentr@unm.edu

Fred Pintz
NMMRA
2340 Menaul, Suite 300
Albuquerque, NM 87107
Ph: 998-9898
Fax: 998-9899
nmpro.fpintz@sdps.org

Albert Rizzoli
Presbyterian Health Plan
P.O. Box 27489
Albuquerque, NM 87125-7489
Ph: 923-5709
Fax: 923-5247
mdriz@aol.com

Timothy Sanchez-Brown
Dept. of Biology
UNM
Albuquerque, NM 87131
Ph: 277-5340
Fax: 277-3838
timsb@unm.edu

Gary Simpson
NM Dept. of Health
1190 St. Francis Dr.
Santa Fe, NM 87502
Ph: 827-2471
Fax: 827-0163
garys@doh.state.nm.us

Rick Ulibarri
LANL, MS A013
P.O. Box 1663
Los Alamos, NM 87545
Ph: 665-0140
eboy@lanl.gov

Terry Yates
Dept. of Biology
UNM
Albuquerque, NM 87131
Ph: 277-9740
Fax: 277-0304
tyates@sevilleta.unm.edu

Al Zelicoff
Sandia National Laboratories
P.O. Box 5800
MS 1203
Albuquerque, NM 87185-1203
Ph: 844-8020
Fax: 844-0600
apzelic@sandia.gov

Appendix A

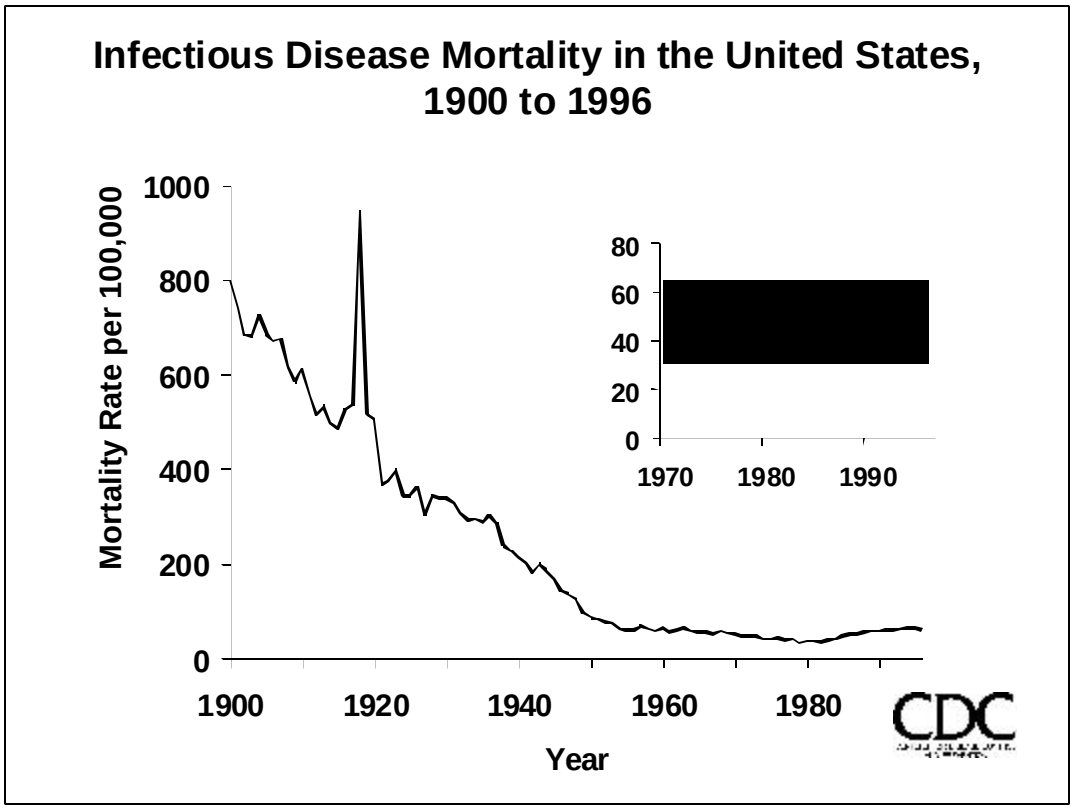
New Mexico

Statewide Immunization Information System Initiative

Objective

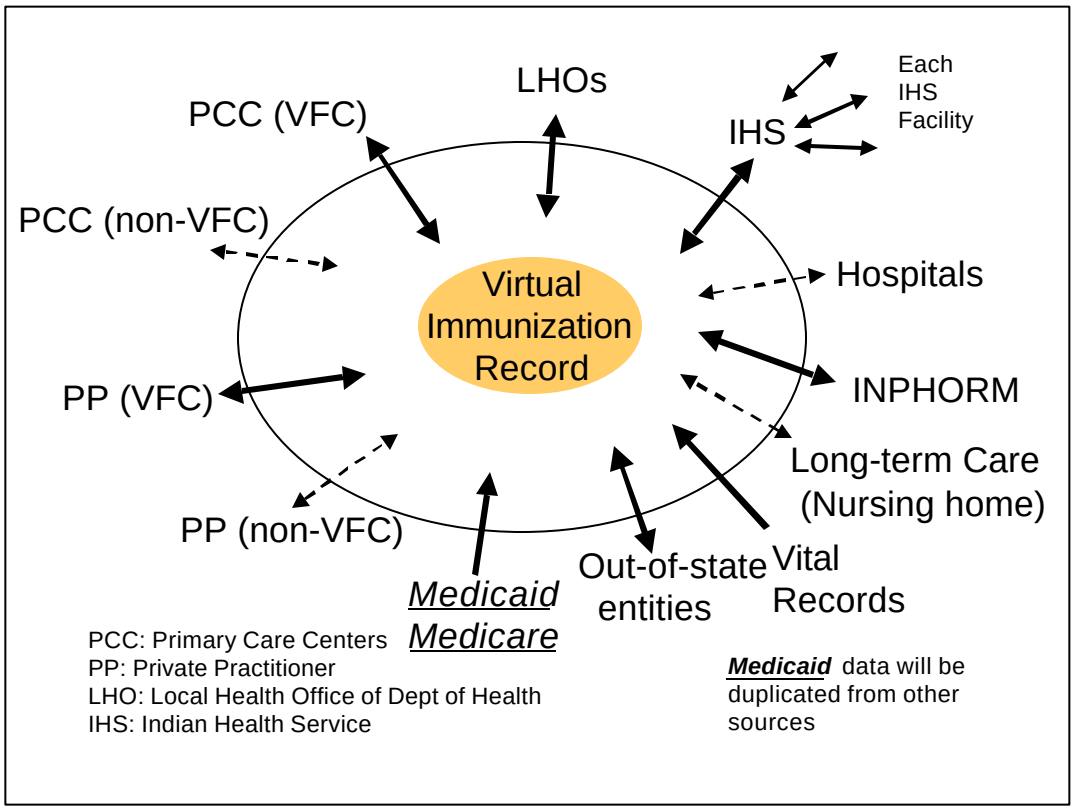
A single, compelling measurable goal:

To immunize, age-appropriately, 90% of New Mexico's children and high-risk adults by 2000(?).



Vaccine Preventable Infectious Diseases

- Diptheria
- Tetanus
- Pertussis
- Measles
- Mumps
- Rubella
- Varicella
- Hepatitis A
- Hepatitis B
- Influenza A&B
- Pneumacoccal Disease
- Poliomyelitis
- Haemophilus influenza type B
- Rotavirus



NEW MEXICO Vaccination

Immunization
Wide Area Network
Distribution

(W.A.N.D.)

of

Enchantment

PARTNERS

- University of New Mexico Health Sciences Center
- Cimarron-University of New Mexico
- Lovelace Health Systems
- Presbyterian Healthcare Serv.
- St. Joseph Healthcare
- Blue Cross/Blue Shield of NM
- U.S. Indian Health Serv.
- NM Primary Care Assoc.
- NM Medical Society
- NM Pediatric Society
- American College of Physicians, NM Chapter
- Infectious Diseases Society of America, NM Chapter
- New Mexico Medical Review Assoc.
- NM Department of Health
- Health Policy Commission
- Health Data Alliance
- Los Alamos National Laboratory
- NM Childhood Immunization Coalition

Proposed Functionality

- Enrollment at birth or when a person enters the healthcare system: “cradle to grave” concept
- Core data set, allowing unique identification of individuals
- Privacy and confidentiality protections and security mechanisms
- Timely collection and editing of data by individual provider system
- Quality assurance and data integrity components
- Rapid and interactive access for all providers
- Flexibility and ease of use

Proposed Functionality continued

- Rules-based logic system for predicting current individual immunization requirements at point-of-service
- Capacity for site-specific reporting and analysis, for aggregating data statewide, for vaccine inventory management, for reporting adverse reactions, and for reminder-recall systems
- Linkage with existing, provider database systems
- Geographic Information System (GIS) capabilities, and mapping functions
- Provider/user interface-driven process design

Appendix B

Health Care Facility Database

Geographic Access Data Systems (GADS)

Need:

- Health Services Research, GIS
- No single source of data in comparable format for health care facilities in New Mexico

Data Sources

- Health Policy Commission
- Department of Health
- New Mexico Tumor Registry
- Health Policy Commission
- Division for Government Research
- EDAC
- IHS
- Medicare (OSCAR)
- Others

Work Group

- Department of Health
- Health Policy Commission
- New Mexico Tumor Registry
- Division for Government Research
- EDAC
- LANL
- Medicare (NMMRA)
- Others

Facility Data Base

- All inpatient facilities
- Public Health Offices
- Primary Care Centers
- IHS facilities

Content

- Facility identifying information
- Licensing information
- Bed capacity
- Services
  - basic
  - means
  - personnel

Distribution

- Internet
- Restrictions
- XML